CRGI SNAPSHOT

The Quality of Life of Adults with Developmental Disabilities and their Families
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Background
This pilot study investigated the level of satisfaction in a number of life domains as well as overall life satisfaction experienced by a group of individuals with developmental disabilities in Calgary. The study also examined the quality of life of their families who are often impacted by continuing responsibilities, concerns, and anxieties related to their adult child with developmental disabilities.

Understanding the different aspects of family quality of life—explored through life domains—may be helpful to improve existing policies and supports targeted toward individual and family quality of life. The connections between individual and family quality of life help to identify areas of service delivery where positive changes are possible to support the well-being of all family members.

Objective(s)
This pilot project was conducted to determine the level of satisfaction with quality of life of adults with intellectual disabilities and their families being supported by Calgary agencies.

Method
Twenty individuals and nineteen families were interviewed. The Family Quality of Life Survey (Brown et al., 2006) was used to assess quality of life for family members of participants. The Personal Well-being Index – Intellectual Disability scale (Cummins & Lau, 2005) was used to assess quality of life for individuals with disabilities. Nine life domains were assessed: health, financial wellbeing, family relations, support from others, service supports, careers (including career preparation), leisure and recreation, and community involvement. These life domains were rated on six dimensions: importance, opportunities, initiative, stability, attainment, and satisfaction.

Results
Health, family relationships, and disability services supporting their adult children were the most important domains for family members. Families viewed the support services provided as the most likely to decline in the near future when compared to the other domains. Family relations, health, and work were also worries for these families.

Interesting findings:
- People who felt strongly that their family member’s needs for disability supports were met were also happiest with their family’s health.
- People who were happier with their family’s health also had more financial, career and leisure opportunities, and acted on them.
- The more families fought for and received good disability services, the more they were able to go out and earn money.
- People who had more opportunities to get disability services for their family member also had more opportunities for leisure activities and community involvement.
- People who were happier with their disability services also had more opportunities for leisure activities.
- People who were happier with their family’s quality of life were also more likely to look for disability services and have a good income.
Those who were happier with their disability services and financial opportunities had a better quality of life.

People who felt that their disability services would decrease valued support from others more.

People who were happier with their family relationships, the support they received from others, and their leisure and community involvement were also more likely to see their family health as stable or improving.

People who had more opportunities to get support from others also said they had more opportunities to practice spiritual and cultural values.

People said if they had less support from extended family and friends in the future, their community involvement would be reduced and their spiritual or cultural values would have less impact on their quality of life.

Overall, the adults with developmental disabilities were happy with their lives. They were most happy about their goals, community involvement, and standard of living. They were least happy about their health and future life.

When families valued disability services and felt that their family member was receiving quality services, the adult with disabilities was more likely to see his or her future as secure.

**Conclusions**

Families and adults with developmental disabilities would have less worry and a better quality of life if they were sure that enough disability funding and support would be available for them in the future. It is hard on aging family members to meet the disability needs of loved ones unless they have strong social supports. Services offering help developing family support networks would promote greater family health and wellbeing.

This study interviewed families and adults who were already receiving services through a disability services funded agency. In future, it would be worthwhile to compare the findings from these participants to individuals and families who do not receive any external disability services, or those who manage their family member’s services entirely themselves.

**Lessons Learned**

Investigating the wellbeing of individuals with disabilities should include the study of their families’ quality of life as well. Typically, support services for young children take a family-centered view, but this focus seems to become less frequent as children and their families age. Adults with disabilities tend to have different relationships with their family members than those who do not have disabilities. Their families are often more instrumental in their children’s lives, and play a more active role. For this reason, it is important to formally consider the family context of this population.

The full report can be found at [www.mentalhealthresearch.ca](http://www.mentalhealthresearch.ca)

**References**


**About the Author:** Ryan Geake is the Executive Director for Calgary SCOPE Society. The Calgary SCOPE Society works with people with disabilities who have accompanying mental health or behavioural concerns. The SCOPE Society works with people across the lifespan to assist them to live successful lives in the community.